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Dear Representative Pat Carney,

February 2, 1992

I am writing to enlist your assistance for a situation that I find myself in.

Last January our fourth child, Reid David Putnam, was stillborn by emergency C-section. He was resuscitated and currently is diagnosed with cerebral palsy, epilepsy, and mental retardation. We as a family desire to keep him at home with us where he will receive the love, attention, care and help which he will need in order to reach his full potential while enjoying a high quality of life. Unfortunately Reid's COBRA insurance policy will be expiring this year. Due to his disabilities being preexisting, new insurers will not consider coverage of his current disabilities which brings us to the reason for this letter. For us to financially provide for Reid's care without outside help would require a major portion of our income leaving very little for the rest of our family to live on. Yet our income is too high for Reid to qualify for Medicaid.

All of the current options which would permit Reid to qualify for Medicaid are unacceptable choices in our eyes. All of them encourage the breakdown of the family unit, whether directly or indirectly. As the state statutes currently read, the following are the only ways in which Reid is able to qualify for Medicaid: 1) The family can "spend down"-a reduction of assets to include home ownership, college funds, savings accounts, personal property, etc.-until we are at the level of poverty which would qualify us for Medicaid (this is about \$32,000 a year for a family of six). It is not right that our other children would have to live under these circumstances just so that their brother would be able to receive the level of medical care which he requires. I also have a difficult time with the idea of entering the welfare system because I was brought up with a strong work ethic. I have always believed that we should provide for our own needs. Unfortunately we are unable to provide for Reid's needs without assistance. However, why must we be reduced to the poverty level where we could not provide for our other children and our own needs? 2) Reid could be placed up for adoption at which time he would qualify for Medicaid. 3) Reid could be institutionalized at which time he would qualify for Medicaid (Room and board at Our Lady of Compassion is \$72,000 a year; Harborview in Valdez is over \$118,000! These amounts would not include physical therapists, occupational therapists, doctor visits, medicines, etc.) 4) Reid could be placed in foster care at which time he would qualify for Medicaid. Options 2, 3, and 4 are ridiculous! I love my son and I want him to be at home with us. 5) We could legally separate/divorce in which case one of us could be employed and pay child support and the other one of us would have custody of Reid and our other children. Statistics already show that a family which has a handicapped child is at a 66% risk for divorce. My husband and I have no desire to add to this statistic! 6) We could move out of Alaska to one of the 47 states which have some form of a Medicaid waiver currently in place. We have all of our family residing in Alaska. The grandparents, great-grandparents, aunts, uncles, cousins, and in-laws are ALL vital members of our support system and it would be very difficult if we could not live near them. The love and support demonstrated by them has made this past year a very unifying one for our entire extended family. As you can see all of the choices which we as a family face penalize us because we have chosen to keep our son at home with us.

Recently the governor has come out in support of Medicaid Waivers which I am grateful to see. The fear which I have with the Medicaid Waiver is that the number of waivers will not be enough to accommodate our family. A report by the Medicaid Task force states that there are between 100 and 200 children who would meet the qualifications for a Medicaid Waiver. This same report states that the number may be off by 100. So, if only 10 to 20 waivers are given out the first year of Alaska's adoption of the waiver process and 40 the second year you can see that my fear for Reid is well justified. It is for this reason that I am also seeking your support for both the Medicaid Waiver and House Bill Number 438 which will allow for all Alaskan children which are at risk of institutionalization and meet the waiver standard to be able to receive Medicaid without the parents income being considered.

The time to take action is now. It is for this reason that I am writing to enlist your support of these bills which will enable Alaskan families like ours to keep our medically complex children at home with us.

Thank you for your timely support.

Laurel Pfanmiller-Putnam
908 W. 57th
Anchorage, AK 99518
563-7545

Laurel Pfanmiller

3111 C STREET, SUITE 455
ANCHORAGE, ALASKA 99503
(907) 561-7628

WHILE IN SESSION
P.O. BOX V
JUNEAU, ALASKA 99811
(907) 465-3704

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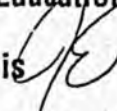
SPECIAL COMMITTEE ON INTERNATIONAL
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LEGISLATIVE COUNCIL

REPRESENTATIVE JOHNNY ELLIS

MEMORANDUM

TO: Rep. Georgianna Lincoln, co-chair
House Health, Education & Social Services Committee

FROM: Rep. Johnny Ellis 

RE: Scheduling HB 438 & HCR 48

DATE: February 7, 1992

Please consider scheduling HB 438 & HCR 48 for a hearing before your committee. These bills relate to home and community based health care for children & adults with disabilities and the elderly.

House Concurrent Resolution 48 urges the State Department of Health & Social Services, Division of Medical Assistance, to apply for Medicaid waivers from the federal government. The department has been working in this issue since Sen. Uehling's bill authorized the Community and Home Options to Institutional Care for Everyone (CHOICE) study in 1990. I drafted the resolution to allow hearings on this issue and to make public the health care needs of disabled and elderly Alaskans. As Co-chair of the Health Care Resources & Access Task Force, I have learned much about Medicaid and the eligibility restrictions that are tearing families apart and preventing people from working and caring for their children.

HB 438 — the Katie Beckett Bill — provides for health care for children with disabilities. The Katie Beckett or TEFRA Option is the most common *option* used by states. Seventeen states have the TEFRA Option, 28 states have waivers and six have both as of Sept. 1, 1989. The Katie Beckett option allows a child to be Medicaid eligible at home by treating the parents' income in the same way it would be handled if the child were in an institution. The option makes *all* kids under the age of 21 — who qualify as needing an institutional level of care — Medicaid eligible for basic hospital doctor care/health services.

Applying for the waivers and adopting the Katie Beckett option is important in many ways. It allows families to stay together, it saves the state money — because the cost of home or community-based care in many cases is up to three times less the cost of an institution — and it creates jobs — because new home and community-based agencies and businesses must develop in many rural areas to keep those families together. Thank you for your consideration of this request.



THE INFANT LEARNING PROGRAM

1266 Ocean Drive, Suite D
Homer, Alaska 99603
Phone 235-6044 • Fax 235-2644



February 11, 1992

Dear House Health, Education, and Social Service Committee Members,

Please support HCR 48 and HB 438 to offer Medicaid options and waivers for home-based care for the elderly and children and adults with disabilities.

The Homer Infant Learning Program provides home-based early intervention services to families with infants and toddlers birth to three years who are at risk or experience a developmental delay or disability. Current grant funding levels are not sufficient to provide adequate frequency of services to the 40 families enrolled, especially in the 14 villages in the catchment area. In addition, 40 families are on the waiting list for services.

With Medicaid Health Care coverage, more children/families could be served.

Sincerely,

A handwritten signature in cursive script that reads "Colleen Powers".

Colleen Powers
Program Coordinator

cc: Johnny Ellis

FISCAL NOTE

STATE OF ALASKA
1991 LEGISLATIVE SESSION

BILL NO. HB 438

Revision Date: _____ Department Affected: _____

Title: Medicaid/Certain Disabled Children BRU: Legislature

Component: _____

Sponsor: Representative Ellis

Requestor: House HESS

COMPONENT SERIAL NO.

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Expenditures/Revenues: (Thousands of Dollars)

OPERATING	FY 92	FY 93	FY 94	FY 95	FY 96	FY 97
PERSONAL SERVICES						
TRAVEL						
CONTRACTUAL						
SUPPLIES						
EQUIPMENT						
LAND & STRUCTURES						
GRANTS, CLAIMS						
MISCELLANEOUS						
TOTAL OPERATING	-0-	-0-	-0-	-0-	-0-	-0-

CAPITAL						
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REVENUE						
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FUNDING: (Thousands of Dollars)

GENERAL FUND	-0-	-0-	-0-	-0-	-0-	-0-
FEDERAL FUNDS						
OTHER						
TOTAL	-0-	-0-	-0-	-0-	-0-	-0-

POSITIONS:

FULL-TIME						
PART-TIME						
TEMPORARY						

Estimate of current year impact: _____

ANALYSIS: (Attach a separate page if necessary.)

Prepared By: House HESS Phone: 465-3759

Division: _____ Date: 2/26/92

Approved by Commissioner:  _____

Agency: _____ Date: _____

Distribution (by preparer): Legislative Finance, Legislative Sponsor, Requestor, OMB, & Impacted Agency(ies).

7-LS1821NG
Lauterbach
2/15/92

CS FOR HOUSE BILL NO. 438 ()

IN THE LEGISLATURE OF THE STATE OF ALASKA
SEVENTEENTH LEGISLATURE - SECOND SESSION

BY

Offered:
Referred:

Sponsor(s): REPRESENTATIVES ELLIS, Koponen, Boyer, Gruenberg, Ulmer, B.Davis, Carney, Bruckman, Donley, Brown, Parnell

A BILL

FOR AN ACT ENTITLED

1 "An Act relating to Medicaid eligibility of persons who are eligible to be institutionalized
2 but who are not in institutions; relating to Medicaid waivers; reordering the priorities
3 assigned to groups of persons served under the Medicaid program; and providing for an
4 effective date."

5 BE IT ENACTED BY THE LEGISLATURE OF THE STATE OF ALASKA:

6 * Section 1. AS 47.07.020(b) is amended to read:

7 (b) In addition to the persons specified in (a) of this section, the following optional
8 groups of persons for whom the state may claim federal financial participation are eligible for
9 medical assistance:

10 (1) persons eligible for but not receiving assistance under any plan of the state
11 approved under 42 U.S.C. 601 - 615 (Title IV-A, Social Security Act, Aid to Families with
12 Dependent Children) or 42 U.S.C. 1381 - 1383c (Title XVI, Social Security Act, Supplemental
13 Security Income);

14 (2) persons in a general hospital, skilled nursing facility or intermediate care

1 facility, who, if they left the facility, would be eligible for assistance under one of the federal
2 programs specified in (1) of this subsection;

3 (3) persons under age 21 who are under supervision of the department, for whom
4 maintenance is being paid in whole or in part from public funds, and who are in foster homes
5 or private child-care institutions;

6 (4) aged, blind, or disabled persons, who, because they do not meet income and
7 resources requirements, do not receive supplemental security income under 42 U.S.C. 1381 -
8 1383c (Title XVI, Social Security Act), and who do not receive a mandatory state supplement,
9 but who are eligible, or would be eligible if they were not in a skilled nursing facility or
10 intermediate care facility to receive an optional state supplementary payment;

11 (5) persons under age 21 who are in an institution designated as an intermediate
12 care facility for the mentally retarded and who are financially eligible as determined by the
13 standards of the federal aid to families with dependent children program;

14 (6) persons in a medical or intermediate care facility whose income while in the
15 facility does not exceed 300 percent of the supplemental security income benefit rate under 42
16 U.S.C. 1381 - 1383c (Title XVI, Social Security Act) but who would not be eligible for an
17 optional state supplementary payment if they left the hospital or other facility;

18 (7) persons under age 21 who are receiving active treatment in a psychiatric
19 hospital and who are financially eligible as determined by the standards of 42 U.S.C. 601 - 615
20 (Title IV-A, Social Security Act, Aid to Families with Dependent Children);

21 (8) persons under age 21 and not covered under (a) of this section, who would
22 be eligible for benefits under the federal aid to families with dependent children program, except
23 that they have the care and support of both their natural and adoptive parents;

24 (9) pregnant women not covered under (a) of this section and who meet the
25 income and resource requirements of the federal aid to families with dependent children program;

26 (10) persons who can be considered under 42 U.S.C. 1396a(e)(3) to be
27 individuals with respect to whom a supplemental security income is being paid under 42
28 U.S.C. 1381 - 1383c because they meet all of the following criteria:

29 (A) they are 18 years of age or younger and qualify as disabled
30 individuals under 42 U.S.C. 1382c(a);

31 (B) the department has determined that

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(i) they require a level of care provided in a hospital, nursing facility, or intermediate care facility for the mentally retarded;

(ii) it is appropriate to provide their care outside of an institution; and

(iii) the estimated amount that would be spent for medical assistance for their individual care outside an institution is not greater than the estimated amount that would otherwise be expended individually for medical assistance within an appropriate institution;

(C) if they were in a medical institution, they would be eligible for medical assistance under other provisions of this chapter; and

(D) home and community-based services under a waiver approved by the federal government are not available to them under this chapter [REPEALED].

* Sec. 2. AS 47.07.030 is amended by adding a new subsection to read:

(c) Notwithstanding (b) of this section, the department may offer a service for which the department has received a waiver from the federal government if the department was authorized, directed, or requested to apply for the waiver by law or by a concurrent or joint resolution of the legislature.

* Sec. 3. AS 47.07.035 is amended to read:

Sec. 47.07.035. PRIORITY OF MEDICAL ASSISTANCE. If the department finds that the cost of medical assistance for all persons eligible under this chapter will exceed the amount allocated in the state budget for that assistance for the fiscal year, the department shall eliminate coverage for optional medical services and optionally eligible groups of individuals in the following order:

- (1) clinical social workers' services;
- (2) psychologists' services;
- (3) chiropractic services;
- (4) adult dental services;
- (5) emergency hospital services;
- (6) treatment of speech, hearing, and language disorders;
- (7) optometrists' services and eyeglasses;
- (8) occupational therapy;

- 1 (9) mammography screening;
2 (10) prosthetic devices;
3 (11) medical supplies and equipment;
4 (12) clinic services;
5 (13) physical therapy;
6 (14) personal care services in a recipient's home;
7 (15) prescribed drugs;
8 (16) long-term care noninstitutional services;
9 (17) inpatient psychiatric facility services;
10 (18) intermediate care facility services for the mentally retarded;
11 (19) intermediate care facility services;
12 (20) individuals described in AS 47.07.020(b)(10);
13 (21) individuals under age 21 who are not eligible for benefits under the federal
14 aid to families with dependent children program because they are not deprived of one or more
15 of their natural or adoptive parents;
16 (22) [(21)] skilled nursing facility services for persons under age 21;
17 (23) [(22)] aged, blind, and disabled individuals who, because they do not meet
18 the income requirements, do not receive supplemental security income under Title XVI of the
19 Social Security Act, but who are eligible, or would be eligible if they were not in a skilled
20 nursing facility or intermediate care facility, to receive an optional state supplementary payment;
21 (24) [(23)] individuals in a hospital, skilled nursing facility, or intermediate care
22 facility whose income while in the facility does not exceed 300 percent of the supplemental
23 security income benefit rate under Title XVI of the Social Security Act, but who, because of
24 income, are not eligible for the optional state supplementary payment;
25 (25) [(24)] individuals under age 21 under supervision of the department, for
26 whom maintenance is being paid in whole or in part from public money and who are in foster
27 homes or private child-care institutions.

28 * Sec. 4. DEPARTMENT TO SEEK WAIVER. The Department of Health and Social Services shall
29 seek approval of a waiver for home and community-based services under 42 U.S.C. 1396n for persons
30 who are Medicaid eligible and who would otherwise require a level of care provided in a hospital,
31 nursing facility, or intermediate care facility for the mentally retarded, in the absence of home and

1 community-based services.

2 * Sec. 5. (a) Sections 1 and 3 of this Act take effect on the 180th day after the effective date of
3 Medicaid plan amendments approved by the federal government under which the state would implement
4 waivers of the type applied for under sec. 4 of this Act.

5 (b) The Department of Health and Social Services shall notify the revisor of statutes as to the
6 effective date of the plan amendments referred to in (a) of this section.

7 * Sec. 6. Sections 2 and 4 of this Act take effect immediately under AS 01.10.070(c).



FRAN DURNER / Anchorage Daily News

Elaine and Douglas Hurley with 18-month-old daughter Brianna.

Caught in a Health Care Trap

Medicaid rules push
middle-class family toward poverty

By JAY BLUCHER
Daily News reporter

Douglas and Elaine Hurley had it all — a new marriage, good jobs, a promising future. The only thing that would have made their lives perfect, they thought, was a child.

But when their daughter, Brianna, was born with severe medical problems, the Hurleys were forced to surrender much of what they had so Medicaid would pay for her care.

Eighteen months ago, before Brianna's birth, the Hurleys were a two-income family earning more than \$40,000 a year. Douglas, 24, was working full time as a baker and commercial fisherman, and Elaine, 26, was holding down three part-time jobs as a secretary and bookkeeper. They had been married for just two years.

"We scrimped, saved and planned for this baby and thought we had what people think of as the American dream — money for a down payment on a house, college funds, savings accounts — if not attainable, then at least in sight," says Douglas.

Brianna was born with cerebral palsy and epilepsy. She also has severe brain damage caused by viral encephalitis contracted in the womb. The disease, often fatal, causes paralysis.

At 7 months old, Brianna also suffered a stroke.

Some doctors tell the Hurleys that Brianna might learn to walk

by age 6 or 7. Others, such as Dr. Jerome Mednick, a pediatric neurologist in San Francisco, say she will never walk or talk.

Now, when other children her age are toddling, Brianna has only recently been able to muster the muscle coordination to wave her right hand. She cannot support herself upright or crawl, and the entire left side of her body is impaired. She is like a limp rag doll, with the motor skills of a 2-month-old.

While the Hurleys accept Brianna's special needs, the cost of caring for her at home was unexpected.

"We thought to ourselves, 'OK, we'll deal with it; there's help available for families like us,'" says Elaine.

But little did they realize that their decision to care for Brianna at home would force them to cash in their lives for a welfare check.

Since birth, Brianna has required extensive medical attention ranging from emergency hospitalizations — as when her seizures caused a semi-comatose state for 30 days — to regular visits with pediatricians, neurologists, nutritionists and other specialists. As a disabled infant, she also receives regular occupational, physical and speech therapy services through the state's Infant Learning Program.

She's had every manner of diagnostic test, and these continue.

At a big price.

The specialized infant formula she needs to gain weight costs \$75 a case, and lasts only a week because Brianna still cannot eat solid foods. The medications needed to control her seizures cost \$700 per month. Her medical bills average \$4,000 a month. And in Brianna's future looms extensive orthopedic surgery and probably an expensive liver transplant. (The drugs that help control her seizure have damaged her liver.)

The Hurleys estimate Brianna's medical bills will cost \$60,000 annually for the next five years. More than \$20,000 remains unpaid now.

At first, the couple had reasonably good medical insurance through Douglas' employer. It paid 80 percent of the family's medical costs. But after just three months in which Brianna's total medical costs topped \$60,000, Blue Cross of Washington and Alaska reduced its coverage to 50 percent.

Douglas' employer at the time, William Pargeter, who owns Harry's restaurant and owned the now-defunct Kayak Club, could have continued the higher coverage, but at greater cost.

Pargeter says he was acutely aware of the Hurleys' high medical expenses because the Kayak Club was in the midst of a bankruptcy reorganization at the time and he

Please see Page D-2, TRA!

TRAP: Medicaid rules embitter coup

Continued from Page D-1

was looking for a new health insurance plan for his employees.

"But this family's high medical costs made the insurance companies leery of accepting the whole group," he says. "In fact, one carrier flatly refused to carry us as long as Douglas was employed with us."

Rather than offering his employees a health plan that excluded the Hurleys, Pargeter instead opted for a less comprehensive Blue Cross plan for all.

Blue Cross officials would say only that the company opted for a less expensive health plan.

Other insurance companies wouldn't accept the family because Brianna's medical needs were "pre-existing."

The Hurleys soon owed thousands of dollars with no hope of ever repaying it on their existing incomes. Threatening phone calls from bill collectors now punctuate their days. Their credit ratings are ruined.

"We were taking food out of our own mouths in order to send \$10 here, \$20 there, for medical bills left unpaid by our insurance, but we were falling hopelessly behind," says Elaine.

The couple realized their only option was Medicaid, the federal health-care program administered by individual states to help the poor. But Medicaid has a strict income limit, and the Hurleys exceeded it.

This family of three, to qualify for Medicaid, would have to begin living on \$1,334 a month, before taxes. Or, as they were told by Medicaid officials, they would have to "spend down to 133 percent of the federal poverty level."

This meant Douglas had to quit his job in September and go on unemployment, which pays him \$760 a month. Elaine could bring in only \$574 a month to stay under Medicaid's limit, so she could accept only part-time work as a bookkeeper.

"I despise living this way, feeling like I'm on the dole looking for a handout, but it's the only way my daughter's medical bills can be paid," says Douglas.

"It's frustrating to be a capable and willing-to-work father who wants to be the provider for my family, and yet be forced by bureaucratic rules to not work," says Douglas.

Income wasn't the only thing they had to cut. The Hurleys were required by Medicaid rules to deplete their savings accounts, college funds for Brianna, certificates of deposit, individual retirement accounts, and to trim their possessions to one car of no more than \$1,500 value, household goods of \$500 value, and \$250 worth of baby furniture.

Every three months, state public assistance officials grill the family about new sources of income — inheritances, church donations or money from other family members.

"It makes me feel so demeaned, like

6 I despise living this way, feeling like I'm on the dole looking for a handout . . . It's frustrating to be a capable and willing-to-work father who wants to be the provider for my family, and yet be forced by bureaucratic rules to not work. 9

— Douglas Hurley

I have no worth, no self-esteem," says Douglas.

Since he's been unemployed, he's gotten several good job offers at considerably more salary.

"I've been reduced to turning down good jobs in order to care for my daughter," he says. "Now isn't that a perverse situation?"

Elaine is just as frustrated.

She worries that the couple may never be able to afford a home, have other children or excel in a career that could provide the security every family seeks.

They could do all that, however, if they did just one thing: Put Brianna in an institution or make her a ward of the state. Then Medicaid would pay for her care and release her parents from income limits.

Unacceptable, say the Hurleys.

"We want to be able to look at ourselves in the mirror and say that we did everything we possibly could to help her, no matter the sacrifice," says Elaine.

Equally distasteful is a third option — for the couple to legally separate. Elaine could accept public assistance as a single parent and Douglas would be free to return to work and pay child support.

"So the state would actually reward the breakup of a loving family," says Douglas sarcastically.

Chris Ashenbrenner, program officer for the state's medical assistance office, says the Hurleys are not alone.

"Because there's no nationwide health plan in this country, people such as the Hurleys are among the gap group, people caught in the middle-class health crisis," she says.

But she also says it's unfair to blame Medicaid.

"It's the whole health care mess in this country and insurance companies that are allowed to drop coverage when claims get too high or certain limits are reached."

David Maltman, executive director

of the Governor's Council for Handicapped and Gifted, says it can happen to anyone.

He agrees that Alaska's current system needlessly impoverishes working families trying to care for a disabled child at home.

Responding to the problem, the council has examined the Medicaid system and recommended improvements to make home care more available to persons with disabilities.

In 1990, the legislature required a similar study by an independent commission known as Project Choice, whose final report will be presented in January. Both the council and Project Choice recommend that the state act for a waiver from federal Medicaid rules.

This would let Medicaid waive income limits for families like the Hurleys.

Alaska is one of only a handful of states that have not adopted a waiver program or something known as "Katie Beckett option."

In 1981 Katie Beckett, a 3-year-old girl from Iowa who, like Brianna, suffered from viral encephalitis, granted a federal waiver by President Ronald Reagan. He cited the case as overregulation.

Since then, a majority of U.S. states have adopted either waiver programs or Katie Beckett options.

Medicaid's Ashenbrenner says Alaska has never applied for this particular waiver or option because the state already has an adequate welfare program, with the most generous eligibility standards in the country.

This rationale, however, does not consider people like the Hurleys: family caught in precisely the regulatory paradox that such waiver programs were intended to address.

The Hurleys seek a waiver or Beckett option as their only relief from poverty sentence.

"Sometimes, you get the impression these Medicaid people think of it as their own money," says Elaine.

She glances lovingly at Brianna who responds with a curious look. When all the frustrations become too much, the Hurleys focus on what most dear.

They shower Brianna with attention. The tiniest of achievements, as simple as a wave of her hand, bring them renewed hope for her future.

"Her wonderful disposition through all of this really makes it easy on my heart, knowing that as difficult as it gets for us sometimes, her love remains unconditional," says Douglas.

He marvels at his daughter's resilience as she sleeps in his arms.

"She's so beautiful, so innocent. She has no idea any of this is happening, no idea that she's . . . different . . . or how difficult all of this has been for her parents," he says.

Brianna stirs.

"Ssshhh, little one. It's OK. Dad's here."

The Anchorage Times

"Putting Alaska first"

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HEALTH CARE PUZZLE

Nothing is 'free'

A REPORT IS due soon from the state Division of Medical Assistance on a project called CHOICE. That's an acronym for Community and Home Options to Institutional Care for Everyone.

The project, undertaken at the direction of the Legislature, will recommend — among other things — that the state apply for a waiver from the federal Medicaid program that would allow compensation for people to receive care in their homes instead of in institutions.

This is laudable. Alaska is the only state that doesn't have a Medicaid waiver along these lines. Right now, for example, if a low-income person with a broken hip, who otherwise would qualify for Medicaid help, wants to convalesce at home rather than go to a nursing facility — that person is denied Medicaid.

This doesn't make sense, particularly when you consider the high cost of caring for people in institutions.

WHY IS Alaska the only state in the union that doesn't have a waiver to cover such instances? Because while we were flush in our oil boom, we didn't apply. Other states started feeling the money crunch before we did and got their waivers for certain services not mandated by Medicaid.

This may present a problem now. It won't be easy to convince the federal government that something the state has been managing to pay for on its own (through social service programs) should now be paid out of the federal treasury.

And should the federal government agree to a waiver, there are still some risks to the state coffers that need to be considered.

If Medicaid will compensate care givers for home care, there is a strong possibility that large numbers may apply for the reimbursement. Some estimates are that 25 percent more people would take advantage of the program than are currently eligible for Medicaid.

Right now, especially in rural Alaska, it's just easier for a family to rally around someone who needs care — whether it be a developmentally disabled child or an elderly person in frail health. No one knows how many more would apply, or whether it would overwhelm the state's required matching contribution to federal dollars.

WHILE OUR citizens and legislators consider and debate the whole issue of health care, they must keep in mind the large role played by government programs such as Medicaid.

Here are a few numbers to consider in light of the changing needs of Alaskans. The facts come from a Project CHOICE packet provided by the state:

- In 1991, \$156 million Medicaid dollars were spent providing health care to almost 49,000 Alaskans. Nearly one-third of the Medicaid budget is spent on long-term health care. And many Alaskans in hospitals, nursing homes or similar facilities could be cared for as well or better in a residential setting.

- The number of Alaskans over 65 is growing at four times the national average. Nursing home care for an Alaska senior costs between \$70,000 and \$110,000 a year.

- Fifteen percent of Alaska seniors over 65 were eligible for Medicaid in 1990.

The question of the state's dependence on the complex Medicaid program is only a tiny part of the health care puzzle facing Alaska today. Last year the state appropriated about \$102 million toward Medicaid. This year, the state approved \$108 million as its share — but some predict that will not be enough.

The cost of health care affects everyone in one way or another — and those who think it's free if the government pays had better think again.

ADN 1/7/92

Medicaid reform

Start with a waiver, but do more

In photographs, Brianna Hurley looks like any healthy, happy 18-month old. The picture that ran in Monday's Daily News showed her sitting on her mother's lap. Her pink sweat shirt had white ponies on it, and her straight brown hair was swept back with a matching pink barrette. She shared the couch with her father and a doll.

But the photograph doesn't tell you the whole story. Yes, Brianna is as sweet looking as they come. And it's obvious her parents, Elaine and Douglas Hurley, love her. But their daughter can't hug her doll, or even sit upright on the couch by herself. Born with cerebral palsy and epilepsy, brain damaged from viral encephalitis, felled by a stroke, Brianna can't walk or talk, and may not ever.

Elaine and Douglas Hurley's life is like that photograph: It turned out different than it looked. It's not just that their daughter was born with the problems she has; they have found the personal strength to deal with that. But their financial resources — their jobs, insurance and savings — proved wholly inadequate in the face of \$60,000-a-year medical bills.

There's something wrong with a system that pays for institutional care but won't help a family that wants to care for its loved one at home. There's something wrong with a system that takes two people with good work histories and tells them they can't work.

Had they put their daughter in an institution, Medicaid would have paid for her care without restricting the Hurleys' income. But the couple wants to take care of their daughter, at home, themselves. So they've had to quit their jobs, deplete their savings and sell off household goods to meet Medicaid's income limitations.

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The state of Alaska can help the Hurleys and families like them by applying for an option — used by other states — that would let Medicaid waive the income limits for families who want to care for disabled members outside of an institution.

But while that's a quick fix — and a necessary one — there is more wrong here than simply Medicaid.

There's something wrong with an insurance company that can reduce coverage just when it's needed most, as happened to the Hurleys. There's something wrong with an insurance industry that can refuse to cover prior conditions or high-risk people. There's something wrong with a system that doesn't address catastrophic illnesses. And there's something very wrong with a system that leaves some 90,000 Alaskans with no insurance coverage at all.

The Alaska legislature can ask for a Medicaid waiver. But that's only a stopgap measure toward ensuring everyone the right to medical care. It's only a reminder of how desperately this country needs to reform its health care system.

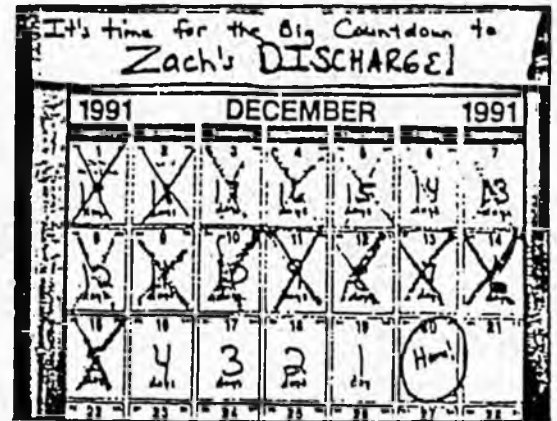
Remember, the family in the photograph could be yours. If this could happen to the Hurleys, it could happen to you.

LIFESTYLES

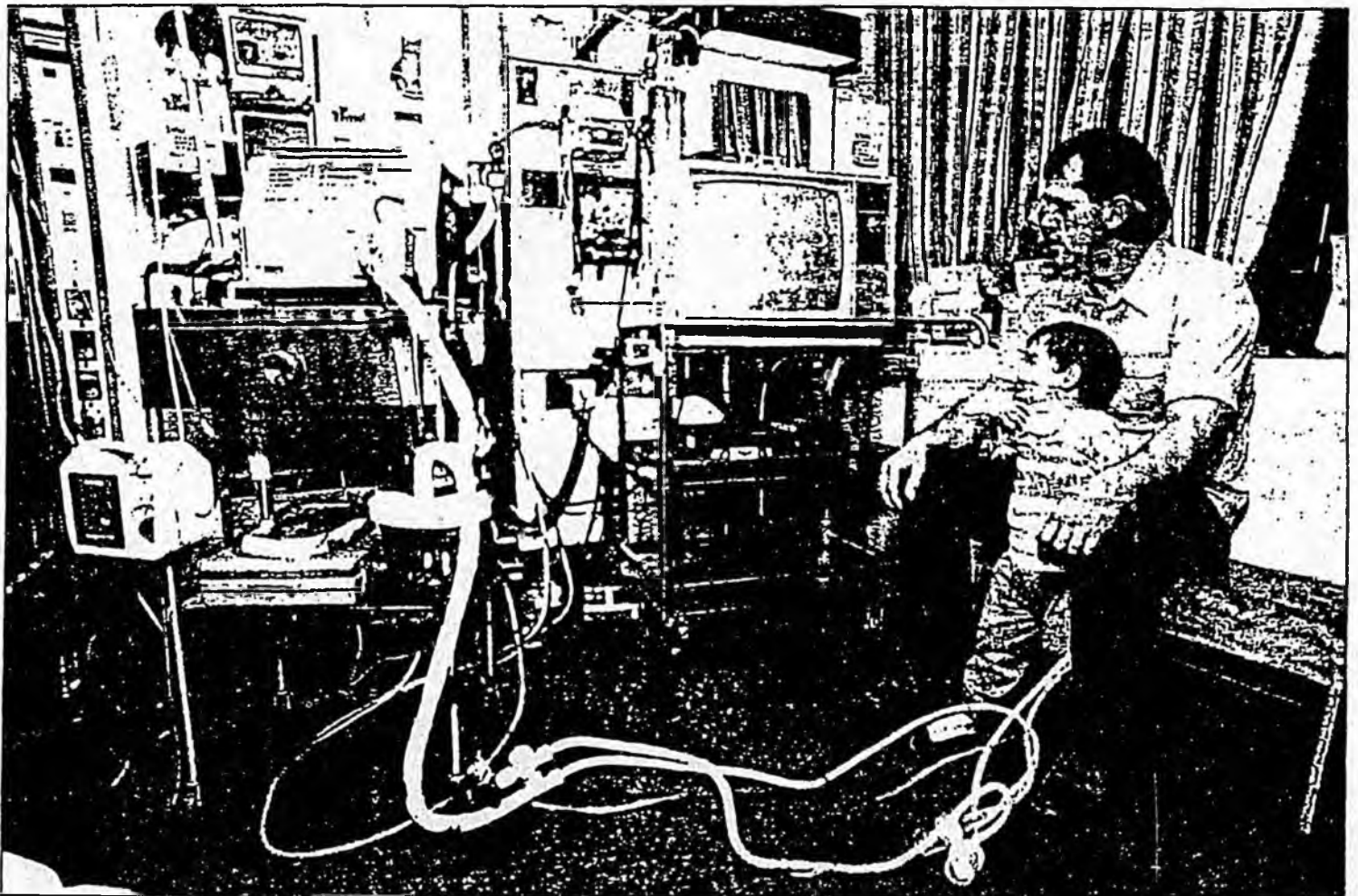
ANCHORAGE DAILY NEWS

SECTION F

BRINGING ZACHARY HOME



If all goes well, Zachary will be home by Christmas.



Zachary and his father, Larry McKenzie, watch 'Sesame Street' in Zachary's room in Providence Hospital's pediatrics intensive care unit.

BM LAVRAKAS / Anchorage Daily News photo



Therapist Gale Andrus trains Zachary to eat normally

YOUNGSTER MAY FINALLY SPEND CHRISTMAS OUTSIDE HOSPITAL

By DEBRA MCKINNEY
Daily News reporter

Life would have been far easier for Larry McKenzie had he just walked away. He and his wife had split up when she was two months pregnant, and hadn't seen each other since. He didn't even know the baby had been born until the hospital called him with insurance questions.

Zachary McKenzie arrived two months early on Dec. 29, 1987. Within hours of his birth, the 3-pound boy was moved to a Seattle hospital with problems so severe he wasn't expected to last the day.

The upper end of his esophagus led to a dead end, not his stomach, and the lower end detoured into his lungs. He couldn't swallow without choking. And acids and other stomach fluids threatened to flow into his lungs and drown him. On top of that was a heart problem for which he needed



Larry has become his son's primary caregiver during the evenings.

HOMECOMING: Youngster may celebrate Christmas outside hospital

Continued from Page F-1

open-heart surgery. Then, during the medevac flight, his stomach filled up with air and burst like a balloon.

Somehow little Zachary held on, though barely.

Larry McKenzie, a Kenai auto mechanic just managing to make ends meet, couldn't begin to afford an intensive-care baby. Some estranged fathers would have shucked the responsibility. McKenzie bought a plane ticket to Seattle.

Four months later, after extensive surgery and two visits from his dad, Zachary was back in Alaska. But his first year was a shaky one. He'd be home in Kenai for a week or two with his mother, Daughn Carpenter, then he'd catch pneumonia or some other bug and be medevaced to Anchorage. His mother could never relax. The last time it happened, he'd been home only 24 hours.

Since then, for the past three years, "home" has been a room in the pediatric intensive care unit at Providence Hospital, a room decorated with stuffed toys, colorful posters and high-tech equipment.

Behind him trails a tangle of tubes and hoses. He must eat through a tube in his stomach. He must breathe through a tube in his throat. Because of a hearing impairment and a tracheotomy, Zachary cannot speak; when he cries, no sound comes out.

That first year, McKenzie drove up from Kenai every Friday night after work to spend the weekend with his son. In 1989, he gave up his job, home, relatives and friends on the Kenai Peninsula and moved to Anchorage to be closer. Eventually he received physical custody (they share legal custody), since Zachary's mother still lives in Kenai and has two other children of her own to raise.

Virtually every night since, McKenzie has spent at Providence, keeping Zachary company and tucking him in at bedtime. Around 9:30 p.m., he puts his boy in a clean diaper, lays him in his crib, closes the curtains and turns out the lights.

"Good night, Bud," he says softly, nose to nose. "See you tomorrow."

"He's pretty much here every single night," says Anita Schillef, a registered nurse on the unit. "We're talking about seven days a week. He's so devoted. It's a real joy to watch."

Lately, members of Zachary's extended hospital family have been keeping their fingers crossed for Zachary and his dad. If all goes



Zachary cries as nurse Sheri Whitthorn and respiratory therapist Sheila Van Cuyk clear his intensive care room of equipment and belongings. Zachary was moved to the pediatrics floor as a step toward his release

the way they hope, this father-son relationship won't be confined to a hospital room much longer. A team consisting of Zachary's doctor, nurses, home health-care coordinators and others are working hard to bring Zachary home before Christmas.

McKenzie has been preparing for this day for more than a year. Last fall, he moved into a bigger, two-bedroom apartment and started getting Zachary's room ready. He built him a little pine bed and a matching toy chest. He hung curtains, pictures and a couple of nets to hold Zachary's bulging collection of stuffed creatures. A quilt made by Larry's mother is draped across the bed, and a supply of shiny toy trucks waits in a corner. A pair of miniature cowboy boots sits atop the dresser.

But McKenzie and the home health care team know from experience not to get too excited about all this until it happens.

"We started on this last year," Schillef said. "Our date was Jan. 1. Then it got moved to May 1. Then we went to July. It's just being continually set back."

The reason is a frustrating one for people who value quality-of-

life issues over financial ones. As hard as Zachary's advocates have been working to get him free, snags in the system have been working to keep him put.

Zachary's medical care has been costing well over \$1 million a year, his father says. Medical insurance pulled him through the first year; then, because he's disabled, Medicaid picked him up.

But now that it's time to go home, Medicaid won't follow. It would pay for Zachary to go into a nursing home, but not his own home.

Medicaid simply won't cover 24-hour nursing care outside an institution, and Zachary is a 24-hour job. This youngster is tethered to a ventilator that needs constant attention. There's no way McKenzie can do it alone. Nobody could.

Zachary and his dad must rely on a patchwork of services to make this work. Medicaid will cover medications, equipment and a limited amount of nursing care, and several agencies — Providence Home Health Care, the Division of Mental Health and Developmental Disabilities, the Anchorage Schip District and others — are picking

together a plan that should provide the necessary nursing, respite and transportation coverage, according to Marchelle Hanson, health care coordinator for this state Division of Mental Health and Developmental Disabilities.

The plan includes 24-hour nursing care assistance for the first couple of weeks, until Zachary and his dad can get settled into their new routine. After the transition period, nursing assistance would be tapered off to about 16 hours a day. If this works as well as everyone hopes, Zachary should be able to start preschool in January.

McKenzie had to quit his job at Grand Auto Supply to do this. He's not thrilled about going on welfare. But he'll do whatever it takes to be there for his boy. And once Zachary gets adjusted, he figures he can start job hunting again.

"I'm getting kind of nervous about quitting work," McKenzie said. "How am I going to support myself? It will be hard. But I know I'm quitting for a cause. I know I have to do this."

While all this is being sorted out, the home health team is plow-

ing ahead with homecoming plans. On Monday, Zachary moved from the intensive care unit to the regular pediatrics floor. The same day, his father moved into the room with him and took over his health care routine.

McKenzie feels confident in his ability to care for his son, and Zachary's nurses agree he's plenty competent. McKenzie has taken extensive courses on all the equipment it takes to keep his son alive. For the past year, he has been Zachary's primary caregiver during his evening visits — feeding him and giving him medications as well as his respiratory therapy. At the end of this trial run, Zachary's nurses believe the two will be more than ready to go home.

Zachary is stronger now than he's ever been. But he still has a long way to go.

His esophagus has been connected through surgery, but, as Dr. Dion Roberts says, "It's not a perfect piece of plumbing." To prevent scar tissue from closing it off, doctors have run a string through Zachary's body that goes in a hole in his stomach and comes out his nose. Should the esophagus start to squeeze shut, a device can be attached to the string and pulled through to stretch it out.

But the biggest obstacle Zachary faces is with his lungs. Both have been severely damaged by pneumonia, as well as aspirated stomach acids and saliva.

Nevertheless Roberts is hopeful for Zachary. It's conceivable that someday he could learn to swallow without gagging. And he could very well learn to breathe on his own. As long as he's growing, his lungs are, too, they could grow strong enough to compensate for some of the damage.

"He has a long, long road to rehabilitation," Roberts says. "It won't be weeks or months. It will be years."

Meanwhile, Zachary's nurses are trying to figure out what they're going to do once their charge really goes home for good.

"You're so happy he finally gets to go home and be with his dad and have the life of a child," one of his nurses, Anita Schillef, says. "But what's he going to do without all his moms?"

"We watched him learn how to crawl. We watched him learn how to walk. We watched him learn sign language. We watched him grow up."

"But no child deserves to grow up in a hospital. He's got a home and a loving father, the most devoted I've ever seen. He needs to go home."